

Women's Health Update

HPV primary cervical screening: What's the hurry?

By Dr Sandy Hall

It has recently been announced that from 2018, the primary test used in cervical screening will change from liquid based cytology to HPV testing.

WHA Policy Analyst Dr Sandy Hall has co-edited an article for the March edition of the New Zealand Medical Journal (NZMJ) by Dr Peter Fitzgerald and Associate Professor Brian Cox on the change.

Here she reviews some of the evidence put forward in the article and the NSU consultation process and asks does this change have the potential to be another unfortunate experiment?

The aim of the cervical screening programme is to detect cellular abnormalities that have a significant chance of developing into cervical cancer. The changes to cervical screening programme mean that the screening test for cervical cancer will be changed from liquid-based cytology (LBC) to a molecular based HPV test in 2018, the time between cervical screening will increase from 3 to 5 years, and the starting age for screening may be raised from 20 to 25 years.

The World Health Organisation (WHO) developed six principles that should underpin cervical screening programmes. They include the overall benefits of screening outweighing the harm, people-centred programmes, providing equity and access, prioritising informed consent, respecting autonomy and confidentiality, regular monitoring and evaluation, and continuous quality improvement. It is therefore reasonable to expect that any changes to screening programmes in Aotearoa New Zealand would be made in this context. However, the process underpinning the current changes has been a departure from WHO principles and from past consultations on the development of the screening programme in Aotearoa New Zealand, which were extensive, wide-ranging and considered.

The proposal to change to primary HPV screening was first made publicly known in September 2015 and a consultation document "National Cervical Screening Programme:

Changing the primary laboratory test" was released by the NSU in October 2015 and gave stakeholders a very short time frame of 3 weeks to respond to these very complex issues.

Moving from the current test to primary HPV testing is not simply a matter of changing the laboratory test. A move to HPV primary screening will require multiple changes to most aspects of the cervical screening programme along with attendant logistical and workforce changes. The NSU also held public meetings in October but short notification times and limited circulation meant overall attendance was poor. At the meeting attended by WHA there were four representatives from Roche, the company who manufactures both the tests and the vaccine, and five representatives from the MOH/NSU. The results of the consultations have only been publically released alongside the decision to implement the changes.

As well as the poor consultative process we believe there are serious issues, which the document did not properly address, and there was a bias as to which research was used. For example, the ATHENA study¹ and the incomplete COMPASS study in Australia² do not fully demonstrate the safety of converting completely to HPV testing, particularly for women under 30 who are not immunised. This is of concern because the levels of immunisation uptake in Aotearoa New Zealand have been relatively low especially compared with Australia who have higher immunisation rates and vaccinate all genders³.

In addition the evidence about the safety of HPV testing at extended screening intervals (proposed 5 year intervals versus the current 3 years) is not certain. As the NZMJ article notes: "Despite the large body of research data presented on the topic in the New Zealand consultation document, the safety of HPV testing at extended screening intervals is not certain^{4,5}. The clinical trials used to model the safety of primary HPV screening are all largely dependent on CIN3 as an end point to justify screening performance and clinical safety. However CIN3 only progresses in a subset of patients and is therefore only a surrogate

Vol. 20 • Issue 1 • Autumn 2016

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for invasive cancer. Therefore there is great interest in the performance of primary HPV screening to prevent invasive cancers^{6,7}." We believe this could pose a serious risk to the health of New Zealand women.

HPV screening also changes the test from a test for cellular abnormalities to one for sexually transmitted infection. The psychological impact of a positive diagnosis of HPV has not been investigated. The effect of this change on participation in screening programmes has also not been investigated. If HPV-testing is shown to be unacceptable to New Zealand women, a switch to offering HPV-testing only could lead to a drop in screening uptake, which could potentially have serious negative consequences for women.

Under the NSU's new screening pathway, women who test positive for HPV 16, 18

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Women's Health Update is a quarterly publication available electronically. It features women's health issues, policy, and up to date information to enable health care professionals, community-based workers, and the public to be at the forefront of women's health.

Women's Health Update is published by Women's Health Action Trust with funding provided by the Ministry of Health.

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[the HPV types responsible for 70% of cervical cancers] will be referred directly to colposcopy, a relatively invasive procedure. It is encouraging that, following concerns raised in the consultation process, the new pathway will include liquid-based cytology being done where women test positive for HPV 16, 18, rather than the originally proposed pathway where women would be referred to colposcopy without liquid based cytology testing.

However, for many women, a HPV positive result may be a transient infection or small lesion that is unlikely to develop into cervical cancer⁸, and the proposed pathway could still lead to an increase in referrals to colposcopy and consequent over-treatment. This could mean many women being referred for further tests that are not needed and being caused unnecessary anxiety.

This also raises the possibility of increased waiting times for colposcopy results. Public sector colposcopy services are already stretched, and this could be exacerbated by an increase in demand and would require additional resourcing or waiting times will increase unacceptably. We also believe this could further contribute to inequities, with women with lower incomes being less able to access private services in cases of long wait times.

There is no robust evidence that a move to HPV screening would increase the participation of groups who currently have poor uptake of the screening programme. Women's Health Action has strongly recommended that one of the ways to ensure more equitable health outcomes is to fully fund screening making it free to all women. Cost has been consistently identified as a barrier to screening⁹, and it is important to acknowledge both direct and indirect costs such as transport, childcare, and lost income from taking time off work.

In fact insufficient attention has been paid to cost in the consultation. No evidence has been produced of cost saving or cost neutral benefits. In addition, the rapid roll-out of the proposed new pathway will result in the loss of much of New Zealand's skilled cytology workforce, and mean that if the new pathway proves unsuitable for New Zealand women, there will be a significantly reduced capacity to meet demand of cytology services.

Screening services must also be equipped to meet the needs of diverse women in New Zealand. The NSU is considering making self-testing for HPV available to women in the future. If self-testing becomes an option, it is vital that is a choice that can be made by women freely and not because of a lack of acceptable services to meet their needs. Nor should it result in these women receiving a substandard service. Those who currently have lower screening access rates include some refugee and migrant populations, rural women, lesbians and women with disabilities¹⁰. We are uncertain if HPV self-sampling will be acceptable to those women who are in the unscreened/under-screened populations.

While the possibility of self-testing may seem to offer the possibility of increased access to screening, we must ensure access to a full range of screening services for all women until there is sufficient evidence to support this hypothesis. We need to have a clearer understanding of what's involved with self-sampling, the sensitivity and accuracy of self-testing, as well as likely costs for the woman. There was no evaluation on the effects of self-testing, removing the opportunity for observation of other health issues that is provided when undergoing screening by a health professional, and the risk of perpetuating disengagement with health services, particularly in groups with currently low access rates.

Knowledge of the purpose of screening varies greatly across women, and may impact on their decision to participate or not participate. This is a particularly salient issue as New Zealand moves to HPV testing as the primary screening method, and it should be an imperative to ensure that women understand that HPV testing is still important even if they have been HPV-immunised, and to ensure any stigma around HPV being associated with sexual activity is addressed. It is therefore important to ensure accurate, detailed information on HPV immunisation, screening, and cervical cancer is made available to all women. The WHO screening principles mentioned above and the Code of Health and Disability Consumer Rights suggest this needs to be done prior to any changes to the screening programme, yet there was a lack of consumer involvement, both as advisors and stakeholders to provide feedback about the proposal throughout the consultation process. There has also been considerable lobbying by immunisation and test manufacturers around changes to our screening programme.

In our submission to the NSU in the consultation, Women's Health Action suggested that the move to HPV testing could bring about some positive improvements but these changes should be incremental and constantly evaluated, and that continuing to test with cytology at the same time as introducing the HPV test appeared to be the safest means of doing this. During the initial roll out of the new programme, information about any risks related to primary HPV screening could have been obtained, and issues such as cancer protection and the potential for over treatment could then be addressed. Importantly, this data would be New Zealand based. It would also allow time to ensure full and equal stakeholder participation and consumer representation. This recommendation has not been taken up.

The lack of wide consultation and haste in which this significant change to health services for women is to be introduced is cause for disquiet. We believe that the decision to implement primary HPV screening alone poses serious and unnecessary risk. We believe it has the potential to reduce the

current level of cervical cancer protection and increase unnecessary referrals for assessment and treatment. The possible physical and psychological costs to New Zealand women are as yet unknown.

By abruptly changing from one screening test to another we may be embarking on a national experiment on New Zealand women.

The article by Dr Peter Fitzgerald and Associate Professor Brian Cox 'The proposed change to primary HPV screening in New Zealand - reasons for caution' has been published in the March edition of the NZMJ.

Women's Health Action's Submission on the proposed change to the NCSP to make HPV testing the primary test in cervical screening can be found on our website www.womens-health.org.nz

Big Latch On 2016 – Save the Date!



In 2016, the Big Latch On will be held on Friday 5th and Saturday 6th August.

The event involves women gathering together at registered venues to breastfeed and to offer peer support to the other breastfeeding women in their community. Family, whānau, friends and breastfeeding supporters from the community also attend the events to support and promote breastfeeding.

Those who can't make it to a Big Latch On event can still take part online by sharing a 'Brelfie' (breastfeeding selfie) on social media to show their support and connect with other breastfeeding women and supporters.

Individuals and community groups can volunteer to organise and host Big Latch On venues across the country. Registrations will be opening in early May, see www.biglatchon.org.nz and like Big Latch On (Aotearoa/New Zealand) on Facebook for updates. www.facebook.com/BigLatchOnNZ/

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Babies are Born to Breastfeed: Breastfeeding Support at Waitangi Day Celebrations

By Isis McKay

Continuing with tradition, Women's Health Action and the Tamariki Ora team from Ngāti Whātua Ōrākei Whai Maia Limited provided a stall space at the Waitangi Festival event on Takapararawhau this year. Waitangi Day 2016 marked the ninth year that Women's Health Action have delivered this stand. The space provides a safe, sheltered and welcoming environment for pregnant and breastfeeding women and their whānau. The aim is to increase awareness and promote positive whānau environments through the following key health messages:

- Babies are Born to Breastfeed
- Every Sleep a Safe Sleep
- Smokefree Waka, Smokefree Whare

Although the day was hampered by heavy rain and showers, the breastfeeding tent catered to a steady flow of visitors throughout the duration of the day.

Visitors to the stand generated some informative discussion. For example, a grandfather who visited the stand asked a number of questions about breastfeeding and



breastmilk, and this led to a discussion about the nutritional components of breastmilk and why we encourage all whānau to breastfeed their pepi. Some of the benefits of the stand were seen when a young, first-time hapu mama visited the tent expressing interest in the Wahakura. She was shown how

to sleep pepi safely, and encouraged to consider breastfeeding as a protective factor and informed how to access a Wahakura through the Tamariki Ora services. Women's Health Action are proud to be part of this collaboration that has grown stronger and more popular amongst whānau every year.

Body Shaming's Harmful Impact on Women's Health

By Meg Rayner Thomas

In November of 2015, some women commuting on the London Underground were handed cards telling them that they are fat. On one side of the card the word fat was written in bold, and the other side explained that the cards were from a group called "Overweight Haters Ltd", an organisation that considers fat people to be gluttonous, wasteful, greedy, and above all, ugly¹. These bullying actions are not only an overseas phenomenon. For example, in Aotearoa New Zealand, women have been shouted at about their size while working out, while plus size models have been ridiculed and trolled online^{2,3}.

It is easy to dismiss such offensive and cruel behaviour as the isolated pranks or beliefs of a small mean-spirited group. However, the reality is that the attitude expressed by these people is the logical result of many years of media exposure^{4,5,6}, governmental policies^{7,8,9}, the neoliberalisation of healthcare^{10,11} and a millennia of misogyny^{12,13}. We live in a culture that, because of technology like Photoshop, not only accepts being inundated with completely unrealistic images of what people look like, but that often even encourages and applauds body shaming for anyone who falls too far outside of the accepted and often unobtainable ideal.

Body shaming can be hard to define because it manifests in so many different ways. Nonetheless, it is important to understand what body shaming is in order to understand why it is harmful and how to put a stop to it. Shame is

a feeling of regret, guilt, or embarrassment that people feel when they have done something wrong. Shaming a person would be to act in a way to cause them to have those emotions¹⁴. Body shaming then, is the act of making a person feel guilty or embarrassed because of a perception that their body is wrong.

Sometimes body shaming is as overt as the examples given earlier in this article. In other instances though, body shaming can take more subtle forms. There are many behaviours that can be body shaming, such as commenting on the food someone eats, remarking on how clothing fits, and making suggestions thought to be helpful on how to lose or gain weight or look better¹⁵. Sadly, these comments and actions have far reaching consequences for the people they are directed towards¹⁶.

Interestingly, those who engage in body shaming often say they do it because they want to encourage others to be healthier¹⁷. Many claim they have a moral obligation to tell others how the lifestyle they perceive others might be living is irresponsible and damaging for society^{17,18}. However, it is impossible to tell anything about a person's lifestyle just by looking at them, and size by itself is not a good metric of health¹⁹. Furthermore, research has shown that feeling shame about one's appearance can lead to depression, anxiety, avoidance of medical care, a decrease in physical activity, and disordered eating^{20,21}. Body shaming actually does more harm than

good to health and wellbeing.

It is important to note that body shaming and its close relative, size discrimination, are disproportionately experienced by women. Several studies have reported that women are more likely to be discriminated against in hiring practices, passed over for raises, and have their performance appraised negatively because of their weight²². Conversely, men actually see an increase in salary and are judged as more competent when they are heavier²³. Even physicians are guilty of this bias. Women are viewed as having a problem weight at only 6 kg above the recommended weight for their height, while men have to be 34 kg over their recommended weight for their height before doctors see their weight as an issue²⁴.

When a group of people feel it is acceptable to hand women cards telling them they are all that is wrong with the world simply because of their bodies, it is time to wonder what it is about our society that emboldens some to take such abusive tactics. The reality is that shaming and discriminating against women for how their bodies look is pervasive, and the actions of "Overweight Haters Ltd" are only one extreme example of attitudes that already permeate culture. It is clear that body shaming is more about policing women's bodies than it is about pushing people to be healthy, and the evidence is clear that body shaming, in all its forms, has profound effects and ultimately is harmful to health and wellbeing.

Taking Action on Fetal Alcohol Spectrum Disorder (FASD): an opportunity to progress women-centred health promotion

By George Parker

The Ministry of Health is in the process of developing an Action Plan to address Fetal Alcohol Spectrum Disorder (FASD), the umbrella term used to describe the range of effects that can occur when a fetus is exposed to alcohol in-utero.

A key focus of the plan will be addressing women's alcohol use during pregnancy, which the available New Zealand data suggests remains high. The Ministry of Health reports in the Taking Action on Fetal Alcohol Spectrum Disorder (FASD) Discussion Document that despite their advice that women who are pregnant or planning to get pregnant should not drink alcohol, 'evidence suggests that about one in two pregnancies in New Zealand are alcohol exposed and around 10% of pregnancies will be exposed to alcohol at high risk levels'¹.

Alcohol is widely understood as a 'teratogen' – an agent that can inhibit normal fetal development and result in birth defects. The Ministry of Health reports that while there is no typical FASD profile, fetal exposure to alcohol can lead to permanent damage to the brain as well as other critical organs, functions and structures, resulting in issues such as visible abnormalities, intellectual and developmental disabilities, attention deficits, poor social understanding, hyperactivity, and

learning disabilities². The relationship between women's alcohol use during pregnancy and FASD is complex. Not all women who drink during pregnancy will have a child affected by alcohol. The timing, pattern and amount of alcohol consumed are key variables, as is the pregnant women's health and wellbeing, with women already experiencing vulnerability who drink alcohol during pregnancy being more likely to have a child affected by FASD³.

The Action Plan to address FASD presents an important opportunity to progress a women-centred health promotion framework that views and addresses women's alcohol use during pregnancy through a sex/gender and intersectional lens. Intersectionality recognises that discriminatory processes, including gender roles and norms, socio-economic deprivation, and racialisation, converge to affect women's lives, health and choices⁴. A women-centred health promotion framework emphasises the range of issues and determinants affecting women's health and encourages the uptake of a respectful and gendered approach to women and alcohol use during pregnancy⁵. This means replacing a fetus-centred framework that typically ignores pregnant women as worthy of health promotion and enhancement in their own right, and tends to focus solely on

fetal or infant health⁶. Additionally, a women-centred approach replaces victim blaming and punitive, shaming attitudes and practices aimed at pregnant women who use alcohol, and instead focuses on systemic change to reduce women's vulnerability and improve their support systems. A harm-reduction framework is consistent with this approach. Harm reduction approaches value and promote a wide range of behaviours and initiatives aimed at mitigating the effects of alcohol use. It recognises that while alcohol-free pregnancies are ideal, a reduction in alcohol use may be a more realistic goal for some women. Collateral improvements in nutrition, vitamin intake, personal safety, food and housing security can also be part of health promotion regarding alcohol use during pregnancy and have been shown to improve outcomes for women and children at risk of FASD⁷.

Women's Health Action has submitted its recommendations to the Ministry of Health for a women-centred and harm-reduction approach to addressing women's alcohol use during pregnancy in our submission on the discussion document.

The submission can be viewed at <http://www.womens-health.org.nz/fasd-submission-2016/>

NOTICEBOARD

IHC WORKSHOPS

24 FEBRUARY – 6 JUNE

The workshops include practical information and strategies for those supporting or working with children with autism. www.ihc.org.nz/autism-and-specialist-support/workshops/

INTERNATIONAL WOMEN'S DAY

8 MARCH

'Pledge for Parity'. Events taking place across Aotearoa. www.internationalwomensday.com/

HEALTH HACKATHON: SOLVING SELF-CARE

18-20 MARCH, AUCKLAND

A workshop designed to enable attendees to collaboratively explore and develop technology solutions in response to the problem of self-care for long term health issues. www.fmhs.auckland.ac.nz/en/faculty/about/news-and-events/events/2016/march/18/health-hackathon--solving-self-care.html

RURAL HEALTH CONFERENCE

31 MARCH – 3 APRIL 2016, DUNEDIN

In association with the NZ Rural Hospital Network and the Rural Health Alliance Aotearoa

New Zealand, the theme is 'Wai Ora, Healthy Environments'. www.nationalruralhealthconference.co.nz/nrhc16

WORLD HEALTH DAY

7 APRIL

Organised by the World Health Organisation, the 2016 World Health Day will focus on diabetes. www.who.int/campaigns/world-health-day/2016/event/en/

CERTIFICATE OF ACHIEVEMENT IN INTRODUCING HEALTH PROMOTION

11-14 APRIL & 9-12 MAY, WELLINGTON

The Certificate - provides an introductory knowledge of the Nga Kaiakatanga Hauora mo Aotearoa Health Promotion Competencies for Aotearoa New Zealand. www.hauora.co.nz/certificate.html

YOUTH WEEK

19-29 MAY

'Aroha Atu, Aroha Mai - Giving Back is Giving Forward'. Events across Aotearoa. www.arataiohi.org.nz/youthweek

HIV WOMEN'S SEMINAR

24 JUNE, AUCKLAND

A seminar on topics relating to women and families living with HIV. www.positivewomen.org.nz

HUI WHAKAPIRIPIRI 2016

5-6 JULY, WELLINGTON

Hosted by the Health Research Council, the theme for Hui Whakapiripiri 2016 is 'Reflections of Māori health research – acknowledging, strengthening, extending'. www.hrc.govt.nz/news-and-media/events/hui-whakapiripiri-2016-wellington

BIG LATCH ON 2016

5-6 AUGUST

Breastfeeding women, partners, whanau and supporters come together across Aotearoa to celebrate and promote breastfeeding. www.biglatchon.org.nz

NZCOM CONFERENCE

26-28 AUGUST, AUCKLAND

Birth, culture and social change – The next 25 years of midwifery in Aotearoa. www.midwife.org.nz/resources-events/nzcom-conference-2016



Women's Health Update is produced by Women's Health Action Trust with funding provided by the Ministry of Health. To receive copies of **Women's Health Update**, make suggestions about future contents or send items for publication please contact: Women's Health Action Trust, PO Box 9947, Newmarket, Auckland 1149, NZ. Ph (09) 520 5295, Fax (09) 520 5731, email: info@womens-health.org.nz
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